

# Experiences of Reciprocal Caring Among Adults With an Intellectual Disability Caring for an Older Family Member

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## Abstract

**Background:** Internationally, many children and adults with intellectual disabilities are continually being supported by their family members to live within their family home. However, as a consequence of the ageing process some family members can struggle to continue to care because of their failing physical and/or mental ill-health. This has resulted in a shift in the parameters of the relationship for some adults with intellectual disabilities with their formerly dependent role evolving into a caregiving one. This has become known as “reciprocity” or “mutual support.” Limited information exists about these “hidden carers” and what services are available to support them.

**Aim:** This article explored the lived experiences of nine adults with intellectual disabilities who provided emotional and tangible support to an ageing family member.

**Method:** A qualitative methodology was employed using semi-structured interviews. Nine participants with mild-to-moderate intellectual disabilities were interviewed within one region of the United Kingdom. The interviews were analyzed using thematic analysis.

**Findings:** Five themes emerged within these narrative accounts: natural transition to caring; the health needs of the ageing family member; support; impact of caregiving and future planning.

**Discussion:** The needs of these unknown hidden carers, and also ageing family members, are immediate and urgent. Policy makers, commissioners and service providers need to examine the type of “in-house” support provided to these new carers if they are to continue living within their family home with their ageing family member, who will also need additional support. Neglecting both cohorts will lead to greater costs to services in the longer term and seriously threaten the quality of life of people with intellectual disabilities and their family carers.

**Keywords:** ageing, future planning, intellectual disabilities, reciprocal caregiving, support

## Introduction

Globally, people with intellectual disabilities are living longer than ever before. As a result, an increasing number of older people with intellectual disabilities are living at home with ageing and increasingly frail family caregivers; a growing number of whom are 65 years of age and above, of whom are ageing in tandem with their adult offspring (Foundation for People with Learning Disabilities, 2018; Taggart, Truesdale-Kennedy, Ryan, & McConkey, 2012; Emerson & Hatton, 2008; Foundation for People with Learning Disabilities, 2006). These family caregivers may be parent(s), sibling(s) or other close relatives

(Barron, McConkey, & Mulvany, 2006; Burke, Taylor, Urbano, & Hodapp, 2012; Lee & Burke, 2018; McConkey, Mulvany, & Barron, 2006).

Ageing family caregivers of people with intellectual disabilities experience a number of unique challenges which increase over time. In many families, the primary caregiver may become increasingly frail resulting in the need for additional care and support (Foundation for People with Learning Disabilities, 2003; Taggart et al., 2012; Yamaki, Hsieh, & Heller, 2009). Over the years, families develop routines and ways of coping with the result that both the ageing family caregiver and the older person with an intellectual disability look after each other. This is known as “reciprocal caring” or “mutual support.” The interdependency within these families, where the person with an intellectual disability adopts a caring role, is common and there is a growing awareness of the importance of reciprocal caring relationships (Grant, 1986; Perkins & Haley, 2013; Walker & Walker, 1998) as well as the needs of older people with intellectual disabilities and their ageing families in policy

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(DoH, 2001, 2003; Foundation for People with Learning Disabilities, 2003, 2010).

More than 1/5 Learning Disability Partnership Boards in England had identified adults with intellectual disabilities who were providing some kind of care and support to an ageing family member such as a mother or father (The Foundation for People with Learning Disabilities, 2003). The care provided to these family members ranges from help with personal care, dispensing medication, cooking and cleaning, to help with shopping and keeping the family member company as they go out (Foundation for People with Learning Disabilities, 2010). It has been concluded, that in many cases, neither the person with intellectual disabilities nor their ageing family members would be able to remain living independently within their local community without this reciprocal caring relationship (Foundation for People with Learning Disabilities, 2010).

Reciprocal caring for ageing family members is globally recognized across different disability populations yet often remains hidden from the perspective of statutory care providers. However, adult children with intellectual disabilities providing care for an ageing family member is a relatively new phenomenon within this field with limited information known about the needs of this population (Hayley & Perkins, 2004).

The increased life expectancy and the emphasis on care within the community has given rise to the number of ageing family carers caring for their older family member with intellectual disabilities (Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2013). The proportion of people with intellectual disabilities living with family members is high. It is estimated that 29 000 people with intellectual disabilities in the United Kingdom alone are living at home with family members aged 70 years or over (Mencap, 2002); in the United States, estimates of nearly three-quarters of people with intellectual disabilities live with ageing family caregivers of which 25% are aged 60 and over (Heller & Factor, 2004). Older adults with intellectual disabilities are more likely to be living with an ageing family carer who themselves have additional support needs (McConkey et al., 2006). Moreover, one in four of these families do not become known to statutory services until there is a crisis resulting in the potential breakdown of the caregiving arrangements (DoH, 2001). There appears to be no fixed point where the balance of caring tips so that both the ageing family member and the older adult with intellectual disabilities begin caring for each other (The Foundation for People with Learning Disabilities (2010). Instead, this is usually a slow process where both parties gradually adapt to their changing role with the passage of time, unless in exceptional circumstances where the family member has an accident or suddenly becomes ill.

The need to plan for the future remains a priority for all families growing older together. Both adults with intellectual disabilities and their family caregivers face increasing challenges as they age and many continually worry about the future when the family caregiver is unable to provide care (Black & McKendrick, 2010; Bowey & McGlaughlin, 2005; Taggart et al., 2012; Walker & Walker, 1998). The problem is perpetuated by a situation whereby all too often, reciprocally caring older families slip through the net between services for older people, services for people with intellectual disabilities and generic care services (Foundation for People with Learning

Disabilities, 2010). These services are generally unaware of the issues associated with reciprocal caring, often as a result of professional boundaries and the blurring of lines of responsibility. As a consequence, some families can fall between all three services and continue to provide reciprocal care with little to no support (Taggart et al., 2012).

There are increasing numbers of adults with intellectual disabilities who are caregivers themselves for an ageing family member, although this care rarely receives any formal recognition (Ward, 2011). The incidence of reciprocal caring is growing, but its true extent remains unknown (Foundation for People with Learning Disabilities, 2010; Holman, Rank, Ward, & West, 2009). The impact of the UK Carers Act (1995) on families caring for a relative with intellectual disabilities has been studied and demonstrates that people with intellectual disabilities (including some who had high support needs themselves) were providing care to their ageing parent(s). However, no one appeared to recognize the situation as one of reciprocal care, and parents generally carried on defining themselves as the main caregivers since they took overall responsibility and exercised control. The authors concluded that reciprocal caring is far more common than is recognized. However, reciprocal caring is often not recognized because ageing family caregivers and their relatives with intellectual disabilities do not recognize the implications of their changing roles and levels of dependency and where they do recognize the situation, there may be a reluctance to inform services for fear of generating an unwelcome or over-intrusive intervention.

More recently, in a study of 91 ageing carers of adult children with intellectual disabilities, caregivers perceived that they gave more tangible and emotional support to their adult children with intellectual disabilities than they received from those children (Perkins & Haley, 2013). This perception of inequitable support by carers was found to be associated with increased depressive symptomology and poorer mental health, in addition to a reduced desire to seek alternative residential accommodation for their adult child with intellectual disabilities.

Although, there is emerging understanding of the mutually dependent relationship that exists among older adults with intellectual disabilities and their ageing family members, from the perspective of the family members (Bowey & McGlaughlin, 2005) limited research has been conducted to gain insight into this phenomenon from the perspective of the person with intellectual disabilities. This study aimed to address this imbalance by exploring the lived experiences of adults with intellectual disabilities providing support for an older family member. There were three objectives to this study: (1) to explore how well the adults with intellectual disabilities were coping with their caring role; (2) to explore whether their experiences mirrored those of other family carers and if not in what ways were they different; and (3) to explore the supports the adults with intellectual disabilities were getting or which they needed to get in order to maintain a caring role.

## Methods

### Design

This study employed a qualitative design. Thematic analysis was applied to analyzing semi-structured interviews with nine

adults with mild-to-moderate intellectual disabilities to explore their experiences of being in a mutually reciprocal relationship with an ageing family member.

### Study Site

The study was carried out in Northern Ireland, a region situated in the north eastern corner of Ireland but governed as an administrative division of the United Kingdom, with its own form of devolved government. Northern Ireland is served by five Health and Social Care Trusts and has approximately 1.8 million residents of whom an estimated 16 366 are recognized as having intellectual disabilities and of these, over 1500 people are aged 40 years or older and are living with ageing family carers (McConkey, Spollen, & Jamison, 2003).

### Participants

Nine people with mild-to-moderate intellectual disabilities currently involved in a mutually reciprocal relationship with a family member participated in this study. Eight participants (six daughters and two sons) were caring for one or both parents and one participant cared for his older brother. The participants were mainly in their 40s (range 41–54 years) caring for a family member in their 60s, 70s, and 80s. Further details of the participants are shown in Table 1. The inclusion criteria specified that participants had to (1) be aged 40 years or older, (2) have a mild-to-moderate intellectual disability, (3) reside with their adult family carer aged 60 years+, (4) provide some form of care and support to their ageing family carer, and (5) have verbal competence and be willing to provide their informed consent.

### Access to the Sample

This study was one phase of an overall three-phase study exploring the needs of ageing carers of older people with an intellectual disability. These participants were identified by their family carers as providing reciprocal care during in-depth

interviews in phase one of the overall study, examining the experiences of carers providing care for their intellectually disabled relative (see Taggart et al., 2012).

### Interview Format

Topics relevant to the area of reciprocal caring were developed and refined to provide the interview schedule. Example interview questions included: Can you tell me about your relative that you provide care for? Can you tell me about the types of tasks that you do to help care for them? Did someone ask you to care for your relative or was it your choice? Can you tell me about the health of your family member? What in particular has enabled you to care for your relative in the home? How do you think caring for your relative has impacted on you? and Have plans been made for the future for your relative if you are no longer able to care for them in the home?

In order to avoid acquiescence in interviews, care was taken to ensure questions were phrased simply and clearly (Finlay & Lyons, 2001). During the interviews, dialogue was kept informal and relaxed. Participants were fully debriefed using “easy-read” materials. The interviews were audio-recorded and transcribed verbatim. Each of the participants was interviewed individually in their own home, with the exception of two participants who expressed that they wished for their family member to be present. It is important to note that the family carers did not contribute to the interview. Interviews typically lasting between 60 and 90 minutes.

### Procedure

Given the emotive nature of the study topic and bearing in mind that the research team did not know potential participants, a preparatory “getting to know you” session was held with each person and the person’s family member, to establish a rapport, to inform the person of the nature and purpose of the project and to identify if the participant was willing to participate in an interview, along with obtaining written consent. Participants were given one week to decide whether or not they

TABLE 1  
Demographics of the participants with intellectual disabilities

Participant code	Participant		Ageing family carer		Length of time caring for ageing family carer (years)
	Relationship to carer	Age (years)	Relationship to participant	Age (years)	
1	Daughter	43	Mum	86	2
2	Brother	54	Brother	68	9
3	Son	45	Mum	69	1
4	Daughter	41	Mum	73	3
5	Son	42	Mum	75	28
6	Daughter	54	Dad	88	6
7	Son	44	Mum; Dad	68;74	3
8	Daughter	49	Mum; Dad	76;75	2
9	Daughter	50	Mum	80	17

wished to participate. In order to avoid response bias, namely the tendency among people with intellectual disabilities toward recency, suggestibility, confabulation and acquiescence (Dye, Hare, & Hendy, 2003), the research team gave careful consideration to the types of open questions that were being asked. Cognisance was also given to the apparent limitations identified with such questions for this population and also avoidance of using leading or abstract questions (Booth & Booth, 1994; McCarthy, 1999). Short, straightforward, everyday words and sentences were used which were less linguistically demanding. Questions were repeated and rephrased if necessary. This strategy helped to reduce anxiety and develop rapport between the researcher and the participant. A pilot study was conducted with two adults with intellectual disabilities: no difficulties were identified, and this data formed part of the overall study.

### Data Analysis

The data were analyzed using Braun and Clarke's (2013) thematic analysis, which includes six phases: familiarization with the data, coding, searching for themes, reviewing themes, defining and naming themes and writing up). The first author conducting the interviews read and reread the interview transcripts to achieve the first phase of "familiarization" of the data. The second phase, "coding" involved collating and coding narrative accounts taken from the interviews. "Searching for themes" was achieved by looking for similarity between the codes and grouping similar codes together. The first two authors shared the analysis of the data by comparing and discussing themes, which accomplished "reviewing themes." The themes that emerged in the analysis in relation to the coded extracts were retained. Similar themes were collapsed together. On-going analysis by the first two authors led to the "defining and naming" of themes. Finally, the "writing up" enabled authors to contextualize the findings in relation to the literature.

### Ensuring Credibility

Validity checks for qualitative research including peer debriefing were performed throughout the research process. The first and second authors assessed the transcripts individually and themes generated were agreed to ensure that identified themes were consistent with the data and were not led by researcher expectations.

### Ethics

The office for Research Ethics Committee in Northern Ireland (ORECNI) granted ethical approval for this study. Written consent was obtained by each of the participants subsequent to them providing verbal consent.

### Findings

Commonalities were apparent in the accounts from each of the individuals interviewed. From this, five emerged from the

participants' accounts of their reciprocal caregiving experience. These themes and their sub-themes are presented below with evidence in the form of narrative accounts.

### Theme 1: Natural Transition to Caring

The participants were asked to talk about their experience of the circumstances leading them to take on their caregiving role. The main theme to emerge was the natural transition to caring, the gradual nature of the change experienced and/or unforeseen circumstances/illness. Most participants took on their caregiving role as a result of a gradual deterioration in the health of their aging family member or "an accident." Many participants stated that they were not asked to take on the role, but rather it was an evolving role that just happened overtime. Unforeseen circumstances were summed up by one participant who described the beginning of her caring role as a result of her father's serious fall at work:

My father took bad that time I was working at X (organisation). He fell and was in a bad way and someone had to look after him. (p.6)

At the other end of the spectrum, another participant revealed the gradual evolving nature of the transition into care by describing how she had cared for both parents but with the death of her father, and, since no other siblings lived at home, she took on the role as the main carer for her mother:

I've been caring all the time cause I was the only girl left in the house cause everybody all went away cause they all went to school and some of them got married, so I always looked after my mother when my father died.....My father used to look after her and I used to look after them. (p.9)

### Theme 2: The Health Needs of the Ageing Family Member

From the participants' accounts, it was evident that their ageing family members had a range of physical health problems which frequently included both "long-term chronic illnesses" and "mobility problems." The health problems reported included arthritis, osteoporosis, sciatica, heart disease, stroke, asthma, chronic obstructive pulmonary disease, diabetes, lymphedema, and diverticulitis. Some problems such as arthritis osteoporosis and sciatica often led to associated mobility problems. Two participants cared for relatives who were wheelchair users and one cared for a parent with mental health problems.

The participants were asked to identify the caregiving tasks they performed on a daily basis. The type of support provided largely centered on daily living tasks such as "preparing meals and cleaning the house." One participant (aged 42) who provided care to his mother (75 years) described his routine:

Make the beds and do the Hoovering, and we've got wooden floors so I would mop them and brush them first, and I would tidy up round the front and round the back,

and I would wash the steps and backyard so I am kept busy. I wash the dishes and make the dinner. (p.5)

Another participant (aged 43) described how she helped her mother (aged 86) to:

Do the cooking and bring that there (rollator) in the car sometimes and take it out again and also help mummy change the beds. (p.1)

All the participants reported that their family member was on prescribed medication. Half the family members were able to take their own medicines while the remaining required assistance. The participants described how they helped their family members by prompting them to take their medication, dispensing their medication and providing them with a “glass of water.” One participant described how she helped to give out oral medication and administer oxygen to her mother who had breathing difficulties. She said:

I would take her medicine to her and help her take her oxygen to bed....I change her water with her oxygen...I give her a nebuliser every night. (p.9)

### Theme 3: Support

The participants were asked “What in particular has enabled you to care for your relative in the family home?” Participants described a range of supports including “formal support,” “family support,” and “respite.”

**Formal support.** Most of the family members received support from statutory services in the form of domiciliary care (i.e., paid carers), who assisted with personal and practical care activities. One participant (aged 49) who provided care for both her parents (aged 76 and 75 years) reported that although she helps her mother to get dressed, her father receives personal care from the paid carers:

I help mummy get her clothes on. Carers come in and they take daddy to the toilet and get him washed. When the carers are not about I have to take daddy to the toilet. (p.8)

Another participant (aged 54) who was the primary carer for her father (aged 88) described how she previously had to care for all her fathers’ needs but now receives formal support:

There are five girls (formal carers) now, morning and dinner time. At the morning at ten o’clock they give him a bed bath and all dress him and get him up and I just have to give him his tablets and breakfast and then at dinner time the girls come in and see if he needs to go to the toilet but it was me who had to do all of that for a long long time. (p.6)

One participant (aged 42) described the benefits of having formal carers now to help him support his mother (aged 75):

There’s a paid carer that comes in in the morning and does wee things for her but I mostly have things done. She’s (formal carer) been coming for two years now. Mother asked for that help....it’s been handy for her to get that help and for me as I play pool for X and we will be heading to England for a match so that week she will come in and the family will take over. It’s good to have that break. (p.5)

**Family support.** Although the majority of participants stated that they received help from other family members in their caregiving role, this support was sporadic. One participant described how she gets help from her extended family:

I get help here from my nieces and nephews who come in now and again....I get help from my sisters but they only come when they are free, they are not here all the time. I hate the night time. (p.3)

Another participant caring for her mother described the irregular support she and her mother received from other family members due to their own family commitments, causing additional stress:

The family does come down but can’t all the time cause they have their own lives and family and other family are too far away so they don’t. (p.9)

**Respite.** There was agreement among all the participants that they needed and valued “respite” in whatever form it was offered as it provided them a break from their caring role. One of the male participants (aged 44) who cared for both his parents (aged 68 and 74) acknowledged the need to have a break from caring by attending the local day center:

I am happy to go there [day centre] three days a week, it gets me out of the house and away from the pressure of helping mummy and daddy. (p.7)

Similarly, another participant (aged 45) caring for his mother (aged 69) revealed:

I just put in for three days at the centre, I could have had five days, but I am happy with the three days as I still have to be in the house for mummy. I just wanted to do that for myself. (p.3)

Only one participant described how she occasionally got a break from caring by attending a residential home for respite and through a community respite worker who takes her out:

I used to go to a residential home but only go there sometimes to get a rest. X (referring to the community respite worker) sometimes takes me out to the shops and she

(mum) looks after herself when I'm away but I still worry she is OK. (p.1)

#### Theme 4: Impact of Caregiving

Many of the participants stated that providing support and care for an ageing family member had impacted on their physical and emotional well-being. Nearly half the participants acknowledged that their emotional well-being was affected. It was evident that caring for their relative often caused them "frustration," "depression," "worry and anxiety."

One participant stressed that the demands of caring for both her parents caused her frustration as she could not always do the things she likes to do:

It's difficult sometimes. It's frustrating because I can't get to watch TV and go out with friends. (p.1)

One participant described the frustration in getting his mother to comply with her medication:

It can be difficult as she has a mind of her own and if she doesn't want to do anything she won't, like taking tablets. (p.5)

Another participant revealed that, prior to getting help from paid carers; she would often get depressed as a result of the constancy of caring for her father and the restrictions of having to stay at home. She revealed how at one point she got so low that she disclosed to her sister that she was at breaking point and was in urgent need of help:

I felt down and under pressure and I wasn't getting out and I was telling X [sister] look I just can't stick this much longer, I had to get out and go somewhere.....I said. Look.... Dad is shouting all the time and I just can't cope anymore...I just wanted to drown myself and do something and X said don't be doing that, I will try and come over and get you more help. (p.2)

It was common for all the participants to be worried and anxious about the well-being of their family members particularly if they were very unwell:

I didn't want to go to work because I was worried about my mum. I used to work on a Saturday, and I used to worry that she would fall out of bed. (p.6)

I only get stressed if mum is not well and I would get concerned about that. (p.8)

Sleep deprivation was also an issue for some carers as evidenced by the following quotation from a 45-year-old man:

I am up and down with my sleep. I worry about mum and I am up and down worrying. (p.3)

Another participant described the worries and anxieties associated with the demands of their caregiving role:

Sometimes I am under pressure and uptight and too anxious cause at times you are in a rush to get to work and you don't want to be late. (p.9)

#### Theme 5: Future Planning

All the participants spoke emotively about what would happen to their older family member if they could no longer offer this support. One participant who cared for both parents stated that "*he did not wish to think about the future preferring to take one day at a time.*" Although the majority of participants had not formally spoken to anyone about the future care of their family member, they expressed a desire for their family member to remain in the family home with support:

I want to stay with them (mum) in the house for as long as possible. (p.1)

However, two participants acknowledged the possible need for their family member to be placed in a nursing home:

It's ok for N (name of brother) to go to a nursing home, I wouldn't want N to stay at home if he got very sick. (p.2)

Well when it comes to that stage maybe she could go into a nursing home, but she is able to go about yet. I haven't spoken to anyone about that. I would speak probably to my social worker and see what he would come up with and what to do with her. I would prefer to stay at home and care for her with extra help. (p.3)

#### Discussion

This reciprocal caring relationship is a crucial one for the older adults with intellectual disabilities and their ageing family members, as well as health and social care providers. To date, research about this relationship has focused almost exclusively on the family carer's perspective (Perkins & Haley, 2013; Ryan et al., 2013; Slevin et al., 2011). This study demonstrates how increased longevity among people with intellectual disabilities has resulted in a reversal of roles with an increasing number of older people with intellectual disabilities currently providing varying degrees of support and care to ageing family members.

The range of health problems experienced by carers and reported by participants in this study mirrored the chronic physical illnesses cited in other studies of ageing family carers of adults with intellectual disabilities (Taggart et al., 2012; Yamaki et al., 2009). These health problems clearly impacted on the carers' ability to participate in the activities of living. Many of the ageing family carers referred to in this study experienced multiple health problems (i.e., heart disease, lung disease and musculoskeletal conditions) and this further limited their ability

to function independently particularly with regards to mobility. This gap was then filled by their relative with intellectual disabilities.

As people with intellectual disabilities age, there is growing recognition that there is a small but significant number of adults with intellectual disabilities living within their family home who take on the role for caring for an ageing family member. As this study suggests, the caregiving relationship evolves into a reciprocal caring relationship overtime involving both tangible and emotional support. Similar findings have been reported elsewhere (Grant, 1986; Walker & Walker, 1998; Walmsley, 1996; Prosser, 1997; Williams & Robinson, 2001; Foundation for People with Learning Disabilities, 2003; Bowey and McGlaughlin, 2005; Knox & Bigby, 2007; Gant, 2010; Perkins & Haley, 2013) describing how people with intellectual disabilities living with ageing family members assume caring responsibilities and provide support ranging from help with shopping, to relatively heavy domestic tasks such as changing beds and the provision of intimate personal care including assistance with medication.

### Implications for Practice

In 2010, recommendations published by the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD, 2010) highlighted the need for services to combine expertise from different sectors, such as older people's services, intellectual disability services, advice services and/or voluntary organizations to effectively support this vulnerable group. However, there is evidence to suggest that health and social care professionals are not aware of the growing incidence of mutual care and therefore are not on the alert to identify warning signals (Foundation for People with Learning Disabilities, 2010). It is fundamental that older people services, intellectual disability services and primary healthcare services are made aware of the impact of the ageing process on adults with intellectual disabilities and their ageing family members, particularly in the context of family caregiving and role reversal.

It has been well documented that social support from formal and informal services as well as family members and friends can lead to a decrease in caregiver burden (McConkey, 2005). This appeared to be the case for participants in this study who identified social support from voluntary and statutory intellectual disability services and extended family members as a key factor in enabling them to continue their caregiving role. Similarly, the personal and practical care provided by paid carers lessened the demand on the person with intellectual disabilities. In keeping with the findings of other studies (Ansello & Janicki, 2000), employment opportunities and day centers were an important source of respite for participants in this study and while the support received from family and friends was often limited and infrequent, it was nonetheless beneficial at both an emotional and practical level. This decline in family support coincides with Bigby (2003) who reported that as people with intellectual disabilities and their parents' age, family support tends to decline and there is increased pressure on formal services to provide a range of support options. The findings from this study have highlighted the negative impact of caregiving on the well-being

of the person with intellectual disabilities. This supports the argument that respite care, tailored to meet the need of the individual with intellectual disabilities and their ageing family carer, is a key component of the support structure required to enable both parties to remain at home. Social workers play a key role in the identification of families who are in this reciprocal caring relationship to assess their needs and provide appropriate care to enable them to remain together in the family home.

It has been well documented that future planning is a major issue of concern among family caregivers of older adults with intellectual disabilities (Bowey & McGlaughlin, 2007; Taggart et al., 2012). This becomes even more problematic as the carer may rely on the person with intellectual disabilities for some kind of support. This may create uncertainty for carers who have always been the providers rather than the recipients of care. It is crucial that these mutually supportive relationships are acknowledged. The needs of both family members and the person with intellectual disabilities must be considered together, as this characteristic of the relationship often represents one of the most significant barriers to planning for the future (Bowey & McGlaughlin, 2007). Although this is a difficult issue for families to confront, services must respond proactively in an attempt to prevent crisis situations developing when the family member becomes too ill to continue their caregiving role. Research evidence suggests that future planning is an extremely sensitive topic for family members (Bowey & McGlaughlin, 2007; Taggart et al., 2012; Walker & Hutchinson, 2019) and the absence of future planning can lead to crisis and emotional trauma for all those concerned (Bigby, 2003; Heller & Factor, 2004). It is crucial, that in order to encourage carers to consider making future plans, that trusting relationships are developed between frontline staff and family members. Equipping staff with the knowledge and skills to work with such families is imperative.

Current assessment practice tends to portray the person with intellectual disabilities as a burden on carers (Hayley & Perkins, 2004). Early identification of families in a mutually caring relationship will enable prompt intervention, which can support and sustain the family staying together in the family home. Failure to provide early, often low-level support can lead to the caring relationship breaking down and more radical and expensive out-of-home service options being needed for both the ageing family member and the older person with intellectual disabilities. To help ageing family members and the organizations supporting them to understand the issues and develop better services, the production of a range of easy read materials for families and professionals should be accessible. The Mutual Care Project (Foundation for People with Learning Disabilities, 2010) has developed a selection of multimedia resources aimed at frontline workers and policy-makers about how best to respond to and support mutual caring. In addition, there are booklets to be used directly with different members of families. These tools aim to help them consider support that may be useful now, in emergencies and to plan for the long-term future.

Robust carers' assessments remain the most important mechanism for identifying and supporting carers. One of the Mutual Care Project outcomes was working with the Valuing People Team and their Network for Carers with Learning Disabilities to develop the resource pack "*Being a Carer and Having a Carer's Assessment: How to get help if you are doing a lot to*

look after another person.” The pack has proven an effective tool to use with people with intellectual disabilities to identify whether they are a carer and what might help. However, it is equally important that the assessment process takes a whole family approach recognizing that many carers with intellectual disabilities get satisfaction from the responsibility of providing care for their ageing family member.

### Strengths

This was a rigorously conducted qualitative and exploratory study which aimed to explore the lived experiences of older adults with intellectual disabilities caring for an ageing family member. This study is limited by the small sample size, nevertheless, there were strong common themes, which indicate shared experiences of people with intellectual disabilities. Although, the study was conducted in a region of the UK where health and social care services are delivered in an integrated rather than a separate system, it is likely that the problems experienced by people with ageing family members are not unique and affect many people globally.

### Limitations

One of the main challenges of this study was the identification of participants in this hard-to-reach group. While all participants were connected to formal intellectual disability services, there are many families who are not in receipt of formal services who are not represented in this study. While Northern Ireland has a joint Health and Social Care approach, community learning disability nurses and community learning disability social workers, other countries may have limited infrastructure to identify this population. Hence community health practices need to be on the alert for such individuals. In addition, despite active efforts to include a diverse range of adults with intellectual disabilities providing reciprocal care for an ageing family member, they were largely female caring for an ageing parent. This meant that it was not possible to compare different groups of carers, for example, male carers. Given the small sample size and the geographical area where the study was undertaken, the findings are not generalizable internationally. Further research needs to be undertaken across the world to find out whether or not these issues are common elsewhere.

### Conclusion

Internationally, reciprocal caring is a natural result of more people with intellectual disabilities surviving into older age and living with ageing family members. The incidence of reciprocal caring is growing but its true extent remains unknown. Reciprocal caring may be a short-term issue, for example, if the ageing family member becomes ill, but for many, as in this study, it reflects the increasing frailty of the family member and is therefore permanent and likely to become more onerous for the person with the intellectual disability and other family members. In response to the growing number of mutually reciprocal care

relationships that exist among this population, it is critical that future research examines the care options and support networks that are available to best suit the needs of these families. This study has a number of policy implications. First, policy makers, commissioners, and service providers need to examine the types of “in-house” supports they provide to these new carers if they are to continue living within their family home with their ageing family member, who will also need additional supports. This is particularly relevant with the ongoing shift in emphasis from institutional to community-based care and it is imperative that the needs of such families are acknowledged and addressed sensitively and without delay. Many families will need support to adjust to these new roles, which will require services to take on a more co-ordinated and family focused approach. It is also important that the person with intellectual disabilities is recognized and gets support, as a carer in their own right (Foundation for People with Learning Disabilities, 2010). The needs of these families are immediate and urgent. Neglecting both cohorts will lead to greater costs to services in the longer term and seriously threaten the quality of life of both family members and people with intellectual disabilities.

### References

- Ansello, E. F., & Janicki, M. P. (2000). The aging of nations: Impact on the community, the family, and the individual. In M. P. Janicki & E. F. Ansello (Eds.), *Community supports for aging adults with lifelong disabilities* (pp. 3–18). Baltimore, MD: Brookes Publishing.
- Barron, S., McConkey, R., & Mulvany, S. (2006). Family carers of adult persons with intellectual disabilities on the Island of Ireland. *Journal of Policy and Practice in Intellectual Disability*, 3, 87–94.
- Bigby, C. (2003). Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability. *Journal of Intellectual and Developmental Disability*, 33, 76–86.
- Black, L. A., & McKendrick, V. (2010). *Careful plans report*. Lisburn: Positive Futures Report.
- Booth, T., & Booth, W. (1994). *Parenting under pressure: Mothers and fathers with learning difficulties*. Buckingham: Open University Press.
- Bowey, L., & McGlaughlin, A. (2005). Adults with a learning disability living with elderly carers talk about planning for the future: Aspirations and concerns. *British Journal of Social Work*, 35, 1377–1392.
- Bowey, L., & McGlaughlin, A. (2007). Older carers of adults with a learning disability confront the future: Issues and preferences in planning. *British Journal of Social Work*, 37, 39–54.
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage.
- Burke, M. M., Taylor, J. L., Urbano, R., & Hodapp, R. M. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, 117, 33–47.
- Department of Health. (2001). *Valuing people: A new strategy for learning disability for the 21st century – A white paper*. London: HMSO.
- Department of Health (DoH). (2003). *Valuing families*. London: The Stationary Office.
- Dye, L., Hare, D., & Hendy, S. (2003). Factors impacting on the capacity to consent in people with learning disabilities. *Tizard Learning Disability Review*, 8, 11–20.
- Emerson, E., & Hutton, C. (2008). Estimating future need for adult social care for people with learning disabilities in England.



- Finlay, W. M. L., & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment*, 13, 319–335.
- Foundation for People with Learning Disabilities. (2003). *Planning for tomorrow: Report of the findings of a survey of learning disability partnership boards about meeting the needs of older family carers*. London: Foundation for People with Learning Disabilities.
- Foundation for People with Learning Disabilities (2006) Planning for tomorrow. Foundation for people with learning disabilities. Retrieved from <http://www.learningdisabilities.org.uk>
- Foundation for People with Learning Disabilities. (2010). *Mutual care project*. London: Foundation for People with Learning Disabilities.
- Gant, V. (2010). Older carers and adults with learning disabilities: Stress and reciprocal care. *Mental Health and Learning Disabilities Research and Practice*, 7, 159–172.
- Grant, G. (1986). Older carers, interdependence and the care of mentally handicapped adults. *Ageing and Society*, 6, 333–351.
- Hayley, W. E., & Perkins, E. A. (2004). Current status and future directions in family caregiving and aging people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 1, 24–30.
- Heller, T., & Factor, A. (2004). *Older adults with mental retardation and their aging family caregivers*. Chicago, IL: Rehabilitation Research and Training Center on Aging with Developmental Disabilities.
- Holman, A., Rank, E., Ward, N., & West, R. (2009). *Sharing the caring: Finding out about support for carers for people with learning disabilities*. London: PRTC and Crossroads.
- International Association for the Scientific Study of Intellectual & Developmental Disabilities (IASSIDD) Comparative Policy and Practice Special Interest Research Group (2010) Policies for a good life in the community: Sustaining and improving community services for people with intellectual disabilities in difficult times. Retrieved from <http://www.iassid.org> ).
- Knox, M., & Bigby, C. (2007). Moving towards midlife care as negotiated family business: Accounts of people with intellectual disabilities and their families “Just getting along with their lives together”. *International Journal of Disability, Development and Education*, 54, 287–304.
- Lee, C. e., & Burke, M. M. (2018). Caregiving roles of siblings of adults with intellectual and developmental disabilities: A systematic review. *Journal of Policy and Practice in Intellectual Disabilities*, 15, 237–246.
- McCarthy, M. (1999). *Sexuality and women with learning disabilities*. London: Kingsley.
- McConkey, R. (2005). Fair shares? Supporting families caring for adult persons with intellectual disabilities. *Journal of Intellectual Disability Research*, 49, 600–612.
- McConkey, R., Mulvany, F., & Barron, S. (2006). Adult persons with an intellectual disability on the Island of Ireland. *Journal of Intellectual Disability Research*, 50, 227–236.
- McConkey, R., Spollen, M., & Jamison, J. (2003). *Administrative prevalence of learning disability in Northern Ireland*. Belfast: DHSS&PS.
- Mencap. (2002). *The Housing Time Bomb: the housing crisis facing people with a learning disability and their elderly parents*. London: Mencap.
- Perkins, E. A., & Haley, W. E. (2013). Emotional and tangible reciprocity in middle- and older-aged carers of adults with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 10, 334–444.
- Prosser, H. (1997). The future care plans of older adults with intellectual disabilities living at home with family carers. *Journal of Applied Research in Intellectual Disabilities*, 10, 15–32.
- Ryan, A., Taggart, L., Truesdale-Kennedy, M., & Slevin, E. (2013). Issues in caregiving for older people with intellectual disabilities and their ageing family carers: A review and commentary. *International Journal of Older People Nursing*, 9, 217–226.
- Slevin, E., Taggart, L., McConkey, R., Cousins, W., Truesdale-Kennedy, M., & Dowling, S. (2011). *Rapid Review of Learning Disabilities, Challenging Behaviour and Ageing commissioned by the RDO: University of Ulster*.
- Taggart, L., Truesdale-Kennedy, M., Ryan, A., & McConkey, R. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities*, 16, 217–234.
- Walker, C., & Walker, A. (1998). *Uncertain futures: People with learning difficulties and their ageing family carers*. Brighton: Pavilion Publishing.
- Walker, R., & Hutchinson, C. (2019). Care-giving dynamics and futures planning among ageing parents of adult offspring with intellectual disability. *Ageing and Society*, 39, 1512–1527.
- Walmsley, J. (1996). Doing what mum wants me to do: looking at family relationships from the point of view of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disability*, 9, 324–341.
- Ward, N. (2011). Care ethics and carers with learning disabilities: A challenge to dependence and paternalism. *Ethics and Social Welfare*, 5, 168–180.
- Williams, V., & Robinson, C. (2001). ‘He will finish up caring for me’: People with learning disabilities and mutual care. *British Journal of Learning Disabilities*, 29, 56–62.
- Yamaki, K., Hsieh, K., & Heller, T. (2009). Health profile of ageing family caregivers supporting adults with intellectual developmental disabilities. *Intellectual and Developmental Disabilities*, 47, 425–443.